



First Steps and the Journey to a Diagnosis of ASD for a Child under Three

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Usually articles that appear in the IRCA Reporter and on the IRCA website are generic and not specific to Indiana. This article is an exception and is addressed to First Steps (0-3) early intervention service providers. While the specifics apply to Indiana, much can still be useful for early intervention providers in other states.

The Need for a Journey toward a Diagnosis of ASD

The incidence of autism spectrum disorder keeps rising. According to the Centers for Disease Control, one out of every 100 children in the U.S. has an autism spectrum disorder (ASD). According to the most recent child count figures compiled by the Indiana Department of Education, the incidence in Indiana is one out of every 101 Indiana school-age children. Autism spectrum disorder impacts the lives of these children and their entire family. All of these identified children typically need some level of special services/adaptations or modifications of educational programs. Families need support in order to cope with the challenge of raising a child with a pervasive developmental disability. Early identification of children with ASD is a national major health/educational initiative because early identification and early intervention (0-5) can have a significant impact on the long term outcome for children with ASD. Indiana children (0-3) typically receive early intervention services through First Steps in natural environments such as the home or childcare center while children (3-5) receive services in more formal programs within the local school system. Much can be accomplished in terms of language, communication, social, and other skill acquisition before a child begins kindergarten. The importance of early identification is exemplified by the recommendation of the American Academy of Pediatrics that pediatricians perform a screening for autism at each child's 18 and 24 month checkups. Early screening will eventually become standard as other trained personnel also assume a role and more responsibility in the early identification process.

The Beginning of the Journey

Identification of children under the age of three often begins in the office of the family physician. Some families will have noted irregularities in their child's development and ask whether their child has ASD; other families have no awareness of red flag signs (see Appendix A). When the signs of an autism spectrum disorder are clear, a physician with appropriate training may make a diagnosis of an autism spectrum disorder or because of the complexity of ASD, refer elsewhere (see Appendix B). When the signs are less clear, physicians vary in terms of whether or not they share their suspicion about a potential ASD with the family; they also vary in terms of the next action step. Some may make a referral for an evaluation by a Health Service Provider in Psychology (i.e., an HSPP psychologist or to a developmental clinic), AND make a referral to the local First Steps program. Others may only refer the family to First Steps. A physician may share his/her suspicions with First Steps or may choose to let local providers make observations that will confirm or reject the suspicion of some disability and the need for a comprehensive evaluation by a specialist. Office appointments are typically time limited to 20-30 minutes, so it is understandable if a physician would defer making a judgment about a serious lifelong disability such as ASD. A diagnosis of ASD is not required for a referral to the First Steps program.

If a developmental delay/disability is suspected by a family, the parents can also make a self-referral to the First Steps program. The child will be evaluated for the First Steps program by an Eligibility Determination or ED Team.

The evaluation lasts 60-135 minutes and is conducted in a place of the family's choosing, (i.e., the family home or other natural environment such as the grandparent's home, daycare, or community settings such as the public library). The evaluation using the Assessment Evaluation and Programming System (AEPS) consists of observation of the child and family interaction patterns, parental interview, and direct performance tasks with the child. The team does not make a diagnosis of a specific disability. Instead, their task is to gather information that will be shared at a program eligibility meeting. Eligibility for the First Steps program is dependent on the child's performance falling below a specific criteria for a developmental area such as communication or motor skills. With parent consent to enter the First Steps program, a plan for intervention called the Individualized Family Service Plan (IFSP) is developed. Programming outcomes are defined, the type of services to best meet the outcomes identified, and service provider(s) (speech, developmental, occupational or physical therapist) selected. A sign-off must occur that signifies review of the IFSP plan by the family physician. Service must begin within 30 days of the parent approval of the IFSP plan. If no red flag behaviors were noted during the ED Team evaluation, there may be no suggestion in the team report of a suspicion of a potential ASD or any other disability.

The Early Interventionist Service Provider and Suspicions of ASD

Children with ASD vary from one another in terms of the specific characteristics exhibited and in terms of the intensity and frequency of manifestation. The typical service provider generally sees a child/family one hour per week in the family home or in a childcare setting. Providers vary in the degree of previous exposure to differing children with ASD. Given the high incidence of ASD, however, it is important for providers to be alert for signs of this disability from the time of the first visit. Often during that first visit, the social behavior of most children is so appropriate that thoughts of ASD are quickly discarded. For others, there may be suspicious infrequent signs and the ASD radar will remain active over several visits. In this interim, the provider may wish to review information about ASD manifestation in young children. An obvious review strategy would be to use the ASD Video Glossary. Video footage was gathered by the First Words Project which showed specific characteristics at various ages and some comparison footage of typical young children and those on the spectrum. The footage can be viewed at any of the following sites:

- <http://www.autismspeaks.org/video/glossary.php>
- http://www.firstsigns.org/asd_video_glossary/asdvg_about.htm
- <http://firstwords.fsu.edu/ASDglossary.html>

Much information is available on the web but a book that every provider might want to own is *Does My Child Have Autism? A Parent's Guide to Early Detection and Intervention in Autism Spectrum Disorders*, written by Wendy Stone, a researcher at Vanderbilt University. The book is easy to read and contains some screening tools that providers may wish to use to guide their own observations and behavioral sampling.

Once there is a sufficient suspicion of the child exhibiting an ASD, then the service provider or primary care provider needs to notify the service coordinator of the potential situation and any other First Step providers for that child. The other therapist(s), if any, can be directed to review some of the same materials to guide their observations or he or she may report already harboring similar concerns.

Sharing Concerns with the Parent

Scenario #1. With the high incidence of autism spectrum disorders and the media exposure, many parents are concerned that their child may have ASD. Often early on in the process of building a relationship, the parent will explicitly ask "Does my child have autism?" It becomes necessary to explain that as a First Steps early intervention provider, one does not make a diagnosis AND that several steps are involved in the process of determining the validity of that potential diagnosis (Appendix B). The parent should be asked what she or other family members

have observed that caused the concern. Often the parent has nothing specific to report. A reasonable response is to briefly summarize criteria i.e., persistent atypical development in the social area, delays and differences in communication skills and repetitive/restrictive or usual behaviors and the red flags (Appendix A). If the parent wishes further information for reassurance and, if an ASD is not suspected, the parent might be referred to the same video materials mentioned for provider review or lent the Stone book mentioned earlier. Encourage the parent to use the Parent Observation Checklist in the Stone book in the interim between therapy appointments and discuss their observations at the next therapy session.

Scenario #2. If a provider suspects an ASD and a parent asks, then it is imperative for the provider to be honest and admit that she/he had some concerns as well and that the team should discuss it. Ask first, however, what has promoted the parent concern. The provider can then pivot off of the parent observations or ask a few other probing questions. It is again wise to suggest the **ASD Video Glossary** and to lend the Stone book, *Does My Child Have Autism?* The service coordinator should be notified of the need for a team meeting or phone consultations with all of the providers and the family. The outcome of such as a sharing of information can only be to recommend a referral or not; no matter how compelling the data, the team cannot make a diagnosis of a disability. It also is important to be clear with the family and other team members that the developmental irregularities noted may be interpreted by the psychologist as suggestive of a different disability or syndrome. It is also possible that the outside evaluation team will delay a diagnosis to check progress between appointments. The service coordinator may compile the observations and concerns and forward to the physician who may make the official referral.

Scenario #3. If a provider suspects an ASD and the parent seems unaware of the concerns, the next step is to contact the service coordinator. It is possible that the service provider is a good observer OR is over vigilant. The service coordinator will want to reach some consensus among providers before scheduling a meeting to share concerns with the family. It is difficult to tell a family that instead of having a speech/language delay that team observations suggest the child MAY instead have a more serious disability. The team will wish to retain a good working relationship with the family and not alarm them unnecessarily. This must be balanced against the ethics of not sharing information. Some team members may be reluctant to initiate the team discussion for fear of jeopardizing the relationship or may feel that the relationship is not strong enough yet to weather such news and thus should be delayed. Parents of children who have eventually received a diagnosis of ASD say that as much as they didn't want to hear the negative information about their child, they disliked it even more when people had a suspicion about THEIR child and delayed discussing concerns with them. With this notion in mind, once the service providers on the team have sufficient informal data, it is important to move forward with scheduling a meeting to discuss concerns and a referral made, if parents concur. With some children who are easier going than others and who can engage to some degree, it may take longer to reach that decision to share concerns with the parents. In these cases, it is still preferable to alert the service coordinator as soon as there is any suspicion, so all service providers are observing early on in the process.

Telling the family has to be an individualized process. In some cases, the service coordinator may talk to the pediatrician/family physician and inquire if the child is due for a required checkup. With some parents, the physician may be the ideal team member to voice concerns and initiate a referral. With other families, if an appointment is not likely in the very near future, the doctor can be informed, and a team meeting scheduled. The service coordinator might identify discussion of observations as the focus of the planned meeting. Following the meeting, the family may need time to process the information before moving forward. Denial and shock are possible initial emotions while other families may express relief because they had been harboring concerns but had not verbalized them. The family may wish to explore the ASD Video Glossary and a few other resources before wishing to proceed with a referral.

Referral for the Family

The service coordinator will offer the family the matrix for HSPP psychologists who provide First Steps evaluations. If the family chooses to seek an evaluation through a non First Steps provider, a list of individuals who have some experience in the area of ASD can be found on the website for the Indiana Resource Center for Autism (IRCA). See the list at: <http://www.iidc.indiana.edu/irca/fdiagnosis.html>. The service coordinator should encourage the family to ask about the provider's experience relative to ASD, his/her experience with children under the age of three, and what will be involved in the evaluation process. Providers such as Riley Child Development Service usually require a referral from the family doctor. The family will need to know what records to bring, what information might be needed, how long the assessment will last, whether the family will know the outcome before they return home, and when a report might be expected. There is also a guide for parents regarding communication issues and questions that might be asked by the evaluation agency. The article, located on the IRCA website, is entitled *Assessment Day: Questions about the Communication Development of Your Young Child...* and is located at <http://www.iidc.indiana.edu/irca/communication/assessmentDay.html>. If parents cannot answer the questions posed in the article, then during the interim between requesting an evaluation and the actual assessment, the family will know what they need to observe or recall.

If there is parent consent, the intervention providers might outline the team observations and concerns for the parents to share with the special assessment team. It can be helpful if the team reports observations/skill levels under the rubric of the three main areas that the assessment provider will be considering if an ASD is suspected. Observations can be grouped under the headings of social interaction, social communication, and restricted/repetitive/stereotypic behaviors.

Provider Services during the Interim

Having a referral for a suspected disability such as ASD does not mean that the child will get a diagnosis, even from a very experienced diagnostic team. Sometimes the signs are not clear enough and the child is put on a follow-up schedule. The child may get a diagnosis on a recall visit when expectations for social behavior are higher and the gap in skills has increased, OR better yet, the child may no longer shows characteristic signs.

Services are driven by IFSP outcomes and not by a diagnosis. The intervention team can note what has been identified as concerns and see if additional services or new outcomes/goals might be needed. For example, providers need to probe whether the child has sensory issues and consider if an evaluation by a First Steps occupational therapist familiar with sensory integration issues is needed. They will want to note: Does the family need help with teaching the child to dress/undress himself, to brush his teeth, to bath, or toilet or diaper? Does the family need help with expanding the child's self imposed highly restrictive diet? Does the family need to know ways to help the child relax or to be more receptive to engagement or active movement? Does the child need further assistance with developing play skills or community skills? Is a behavior consultant needed to help the family cope with outbursts, aggression, or self injurious behavior? Should the IFSP program include goals to assist the child to increase engagement with others or to use gestural communication as an initial communication system?

Many of the intervention techniques identified for children with ASD also work with modification for children that do not have ASD. So, there is no need to wait for an official diagnosis before addressing comprehensive needs. To delay until a diagnosis would be unacceptable since the wait for an appointment might take six months or more. Families should be encouraged to volunteer to take an appointment on short notice for canceled appointments, if this is feasible. While providers can move ahead and encourage the family to do as well, nothing can reduce the family anxiety as much as some definitive resolution of why their child shows some atypical behaviors.

Pre-diagnosis families can be referred to the Stone book mentioned earlier and to *Could it be Autism?* by Nancy Wiseman.

An Affirmative Diagnosis—Now What?

Providers need to understand that if the parent reports that their child has PDD and does not have autism, that they may have misunderstood the diagnosis. Pervasive Developmental Disorder or PDD is the umbrella term that includes autism spectrum disorders. Sometimes the term also is a shorthand version for PDD-NOS. This means that the child is within the milder symptom range of ASD and has less characteristics than one who is diagnosed as having autism. Sometimes this PDD-NOS category is temporary and the child shows more characteristics with increasing age.

A diagnosis might not make a difference in terms of what developmental areas are covered for the child if his/her needs are already being comprehensively addressed. The team may want to visit the issue of assuring sufficient engagement of the child, however. The recommendations from the National Research Council (2001) regarding young children with ASD is 25 hours per week of one to one engagement/interaction, (i.e., with a person, not an toy/activity or the TV/DVD). This does not mean 25 hours of behavioral, speech, occupational or developmental therapy. While some therapy such as speech therapy might be increased to twice a week, within the First Steps model, the goal is to assist the parent to provide enhancing developmental learning within the activities of daily living. If the total of everyone interacting with the child totals 25 hours per week, then the recommendation for minimal time will be met.

What might change within scheduled sessions is the recognition by providers of the need to become even more visual and concrete with the child, to address imitation limitations, to discover additional ways of engaging the child and expanding his/her interests and play-skills, to provide structure, and to plan for generalization of skills. The providers' objectives will be to transfer these skills to the family. Sometimes the family will seek out additional private services.

Parents will learn skills by observing modeled teaching strategies and participation in active coaching, but, they will also benefit from access to books, videos, other parents of children with ASD, and access to resource centers. The main resource center for autism in Indiana is the Indiana Resource Center for Autism which is located in Bloomington, IN on the campus of Indiana University. Parents can visit the IRCA, call and talk to staff about specific questions, receive a free newsletter by email, locate numerous helpful articles on the website, attend trainings offered periodically throughout the state, and borrow books and DVDs about ASD from the Institute library (library materials will be mailed to the family's home). The website for IRCA is www.iidc.indiana.edu/irca and the library is www.iidc.indiana.edu/cedir; the phone number for IRCA is 812-855-6508 and for the library is 800-825-4733. Materials can also be borrowed from Easter Seal Crossroads in Indianapolis; (website www.eastersealcrossroads.org; phone 317-466-1000) and through the Sonya Ansari Center for Autism in South Bend; (website www.ansaricenterforautism.org; phone 574-289-4831). Parents can access <http://www.iidc.indiana.edu/index.php?pageId=546> for local parent group information. First Steps also has the Family to Family program which can be a local support for families facing various disabilities. Their website is www.inf2f.org. Parents may wish to view <http://www.iidc.indiana.edu/index.php?pageId=551> and <http://www.iidc.indiana.edu/index.php?pageId=543> for information about financial support to attend conferences to learn about the disability of ASD. Indiana parents of newly diagnosed Indiana children can also receive a free copy of the booklet *When Your Child is Diagnosed with an Autism Spectrum Disorder and Early Intervention for Young Children with Autism Spectrum Disorder: Recommendations for Designing Effective Programs* by contacting the IRCA through the website or via a phone call.

The Importance of Proactive Intervention.

School personnel often comment that they wish their students with ASD had been diagnosed earlier. First Steps providers are in a position to help make that happen. Providers need to be familiar with the signs of a potential ASD, notice the pervasive pattern and not attend to only a few suspect characteristics, and proactively discuss with the team whether a referral is warranted. Parents need to be assured that ASD may or may not be present but it is

better to know and take appropriate actions than to ignore potential red flags. Similar to medical practices with diseases such as cancer, one has a better outcome if there is early identification and treatment. ASD is no different, even though it is a developmental disability and not a progressive medical condition. Early identification is crucial. First Step providers are on a front line position to have a significant role in the initiation/referral process. They can have an impact on a child's life and the well being of the family that lasts beyond the cessation of their services when a child reaches 36 months of age. Many resources are available to help a First Steps team manage this role.

References

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Appendix A: Red Flags Signs That Suggest a Possibility of an Autism Spectrum Disorder

Characteristics by Age

(Chawarska, Klin, and Volkmar, 2008).

0-12 Months

Less likely than typical infant to look at, and seek out, other people, smile and vocalize at others, limited response to name, unusual sensory and motor stereotypical behaviors, no babbling.

12-24 Months

Limited response to name, poor eye contact, limited social interest and smiling, limited use of gestures, poor imitation, delays in receptive and expressive language, temperamental abnormalities such as extreme passivity in early infancy followed by extreme distress reactions after 12 months of age, difficulties with disengaging from visual attention to objects of interest.

24-36 Months

Diminished eye contact, limited smiling and looking at others, limited interest in social games and turn taking exchanges, low frequency of looking referentially at parents, preference for being alone, delay in motor imitation and symbolic play, direct attention to objects more than to people, limited response to his name, delay in receptive and expressive language, over-attention to nonsocial environment such as focusing on alphabet letters, difficulty adapting to new situations, interest in visually repetitive stimuli such as ceiling fans.

Global Patterns that Occur Less Frequently in Two Year Olds with Autism (Stone)

Showing off, repeating actions that get social attention from others, attempting to please parents, interest in other children, using gestures and facial expression to communicate, directing attention of others by pointing, following the direction of another's point, following simple directions, playing with a variety of toys in diverse ways.

Appendix B: Background Information about the Diagnostic Process for ASD and Beyond

Although much medical research is being conducted about the etiology of autism spectrum disorder, at this time, the diagnosis of an autism spectrum disorder (ASD) is still a behavioral rather than a medical diagnosis. That means there is no medical test that signifies the presence of ASD. The diagnosis is based on the results of a comprehensive developmental history of early development and atypical behaviors, an observation of the child with a focus on social interest and interaction patterns, communicative behavior, and atypical or stereotypical behavior, and some performance tasks. Because of the young age of First Step children, formal testing measures with the child may be very limited. This process can take many hours and involves the coordination of information from several sources. The evaluator, usually a HSPP psychologist, will use the current version of the Diagnostic and Statistical Manual (DSM) criteria to determine if the child meets the requirements for an autism spectrum disorder (with the broader category of Pervasive Developmental Disorder). These criteria can be accessed at <http://www.iidc.indiana.edu/irca/generalinfo/diagnosticcht.html>. Additional assessment information can be accessed at <http://www.iidc.indiana.edu/irca/ServArticles/AccessProcess.html>,

A child with ASD can also have concurrent learning/medical problems and it is possible that he/she may be referred for medical evaluations of sleep and/or eating disorders, seizure disorder, gastrointestinal challenges, acid reflux, a genetics evaluation, vision or hearing evaluation, and so forth. With the exception of a routine vision or hearing evaluation, these would be evaluations ordered by a physician and typically are not services covered by First Steps. In addition to ASD, a child could also be diagnosed with Cerebral Palsy, Down's Syndrome, Fragile X, Tourette's Syndrome, Isodentric 15, Cognitive Impairment, Visual Impairment, or Hearing Impairment among other diagnoses.

The important component of a diagnosis is the process that follows it. Parent support and education is crucial to help families deal with the significant challenge of fostering the development of a child with ASD while balancing the other demands of daily and family life. An appropriate diagnosis of ASD, however, also represents a gateway to other funding/community services such as Children's Special Health Care Services (CSHCS) and Medicaid waiver plans. See <http://www.iidc.indiana.edu/index.php?pageId=365> or call the Indiana Resource Center for Autism for more specific information and guidance; call 812-855-6508. For the waivers, families may be on waiting lists for years. It is important for First Step providers to make a referral that will eventually allow families to apply for this support, if an ASD diagnosis is the outcome of an evaluation.

Vicker, B. (2009). First Steps and the journey to a diagnosis of asd for a child under three. *The Reporter* 14(3), 1-7.